



**Arizona Department of Health Services  
Office for Children with Special Health Care Needs  
Integrated Services Grant**



**ISG – Cultural Competency  
September 20, 2006  
Meeting Minutes**

**Attendees:** N. Burton Attico, MD; Renaldo Fowler; Tom Kirsch, Cozetta LaMore (via telephone); Gloria Payne, Denis Viri, PhD, Melina Perez-McKenna, Jill Wendt, MEd

**Entrances and exits activity:** Entrances within meeting, Joan Agostinelli, Jana Granillo; Exits – Mr. Kirsch

MEETING ITEM	SPEAKER	DISCUSSION	ACTION ITEMS
Welcome	Jill Wendt, ADHS-OC SHCN	Ms. Wendt welcomed the participants to the meeting. Cozetta LaMore was in attendance via telephone as a new member to the ISG Cultural Competency Committee. Tucson's CPSA joined ISG Cultural Competency again by having Melina Perez-McKenna designated as a member, representing CPSA.	*Visit <a href="http://www.azis.gov">www.azis.gov</a> for all ISG information
	Ms. Wendt	Dr. John Molina, who is the Chairperson of this committee, was unable to attend today.	
Introductions	Group	Introductions were made around the room.	
Announcements	Group	Reviewed the handout packet. Announced that everyone should sign the sign in sheet and complete the evaluation forms.	
Review of 6-21-06 Meeting Minutes	Group/Ms. Wendt	Ms. Wendt gave a background on the June 2006 meeting. All information on the Sickle Cell Advocate Initiative by Kristine Buchanan's Quest for Cure Sickle Cell Foundation is available on the ISG website. <a href="http://www.azis.gov">www.azis.gov</a> Kristine is now collaborating with Renaldo Fowler at the Arizona Center of Disability Law and he will talk about a training coming up a little later.	*Sickle Cell Advocate Initiative information on <a href="http://www.azis.gov">www.azis.gov</a> <Cultural Competency link>
	N. Burton Attico, MD Arizona Sickle Cell Anemia Society	Our organization has two web pages. We have a webpage off the national sickle cell anemia organization and we have one of our own. Our own is <a href="http://www.sicklecellaz.org">www.sicklecellaz.org</a> and that is the local one.	*Visit <a href="http://www.sicklecellaz.org">www.sicklecellaz.org</a> (Arizona Sickle Cell Anemia Society)
	Group	Denis Viri, PhD motioned made to accept meeting minutes of 6-21-06. Dr. Attico seconded. Motion and minutes accepted by committee consensus.	*Group approved 6-21-06 minutes by consensus
ISG Task Force and Committee Update	Ms. Wendt	Gave 8-23-06 ISG Task Force meeting update. The ISG Task Force has formed an Executive Task Force Team that has 3 key people. They plan to meet monthly with the committee facilitators.	*ISG Task Force formed an Executive Task Force Team with 3 key people to facilitate effective communication with committees

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ISG Care Coordination Study - Background		<p>Gave background on Care Coordination Study/ Medical Home Project. OCSHCN will be working with the Community Action Teams to recruit 3 medical practices throughout Arizona. The study/project will last for 12 months and the results learned from the data collected will be incorporated in the report to the Governor at the end of the grant.</p> <p>We have a position for Medical Home Program Manager position in OCSHCN office and they will be overseeing the Care Coordination/Medical Home project. That position is in the process of being filled.</p> <p>The grant will fund a screener at the 3 medical practice sites who will conduct specific screening and assessment tools selected by various ISG committees. The state goal is to incorporate the medical home model in the state by 2010. We will hopefully launch the study December 1, 2006.</p>	<p>Visit <a href="http://www.azis.gov">www.azis.gov</a> for ISG Task Force updates</p> <p>*ISG to have Medical Home Program Manager to oversee ISG Care Coordination Study &lt;aka Medical Home Project&gt;</p> <p>*See ISG QI Clinical Committee's May and August 2006 Status Report to Task Force for screening tools to be applied (<a href="http://www.azis.gov">www.azis.gov</a>)</p> <p>*Satisfaction surveys to be done with Care Coordination Study</p>
Handouts - review	Ms. Wendt	<p>Handed out the Maternal and Child Health Care Bureau's definition of CYSHCN and read it to the group. It was noted that Arizona uses the federal definition.</p> <p>Handed out and read the definition of Medical Home to group.</p>	
	Dr. Attico	Addressed the EPSDT correlation within pediatric sites. It was noted that the EPSDT would/could be done at that point as well, within the practice.	*EPSDT correlation to ISG Care Coordination Study – tracking referrals, assigning data elements for state agency cross reference
Community Survey <handout>	Ms. Wendt	<p>Dr. Molina introduced the Community Survey in June and we have been reviewing it off and on since. Ms. Wendt read the statement of purpose and survey for the benefit of Cozetta on the phone.</p> <p>Community Survey tabled at this time. Questions for further discussion include:</p> <ul style="list-style-type: none"> <li>*How would data be quantified?</li> <li>*Who will distribute it and how?</li> <li>*How to get to the most vulnerable populations</li> <li>*What about homeless shelters?</li> <li>*How to get to the at risk populations</li> </ul>	*Community Survey tabled for next meeting with Dr. Molina in attendance
		ISG Parent Action Council (ISG PAC) reviewed the survey and offered comments. Please see attached documentation of ISG PAC's comments on the Community Survey.	*See attached documentation for ISG PAC's comments on the Community Survey

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ISG-PAC Family Profile Review – <handout>	Ms. Wendt	Gave background on the ISG PAC Family Survey. The ISG PAC has a Family Profile they would like for us to review. They want to give it to the parent action leaders that we pay out of our office that we pay to do training, advocacy, etc. to see what their strengths are.	
	Group	There was discussion on the Family Profile from ISG PAC. Some responses outlined were: *Question One was for each member of the family. *Family Profile focuses on a modern content, it plays an important role to have understanding of the traditional beliefs as far as disabilities. Many people will rely on traditional belief and values in answering. People are driven by their tradition and seeking healthcare is tied into the traditional. Need to make modern work with traditional.	
		*Second question - "In your community" should be taken out. If they have to leave, they may not relate to that question.	
		*Second question - are you asking me if I am getting healthcare. Are you asking me if I am getting insurance? And is it paid for? People don't necessarily know what behavioral health is.	
		*Reference CHIP program on Family Survey	
		*Question 2 - are they checking all the yes and nos? It gets redundant.	
Entrances/Exits		Ms. Jana Granillo, ADHS-Arizona Minority Health Office entered the meeting at this time. Ms. Joan Agostinelli, ADHS-OCSHCN entered the meeting at this time. Mr. Kirsch exited the meeting at this time.	
Educational Rights of Students with Sickle Cell Training Seminar	Renaldo Fowler, AZ Center on Disability Law	<p>Handed a flyer out to the group on the upcoming seminar being presented at the Arizona Center for Disability Law. "Educational Rights of Students with Sickle Cell" on October 25, 2006.</p> <p>We are collaborating with Kristine at the Quest to Cure. It's a self-advocacy seminar. Kristine will talk to parents about self advocacy and what parents need to do for self-advocacy. We are networking with IDEA (AZDOE), the 504 plan, and educational facilities. Students are welcomed to come to the training. Post secondary and employment accommodations will be addressed and linked.</p> <p><u>Topics surround basic advocacy skills.</u> What parents need to do when they talk with their doctor for instance. Carolyn Harrison, MD is on the agenda. She will talk on the impact of sickle cell on learning and what the current research with sickle cell kids is. Topics from nutrition, silent strokes, attention span, pediatricians, all the things happening with sickle cell kids.</p> <p><u>Seminar's multiple focuses:</u> – How does the state use the law? Have schools and parents been able to use the state law and apply it? How do we educate the kids with sickle cell? How do you qualify for the 504 plan – what it is, services available. What are the special education services? Are there regular classes? Is there special assistance to the kids with sickle cell? Behavioral and decision making skills of kids, what is it? Regular education to 504 to special education. We will cover the gambit. We really want to get parents there.</p>	<p>As Center on Disability Law – "Educational Rights of Students with Sickle Cell" training seminar: Wed., October 25, 2006 6pm – 9pm 3839 N 3<sup>rd</sup> St. Ste. 301 602-274-6287 1-800-927-2260</p> <p>*Benchmark organizations: -DDD Planning Council -IHD (university based) -Az Center for Disability Law</p> <p>*Visit <a href="http://www.acdl.com">www.acdl.com</a> for resources</p>

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	Dr. Attico	Addressed the legal issue of having a chronic disease and being out of work for periods of time. How can it be addressed with adult accommodations? The ability to tele-work should be a common accommodation. They can be productive even if they are ill. They are taking care of the kids, but they aren't taking care of the adults	*Legal issue: Chronic disease, out of work for long periods of time, but not enough to qualify for programs.
Questions /Discussion	Cozetta LaMore	What is the mechanism to tap into the care coordination for this particular population? Are they connected with a case manager, home based care, medical home?	
	Gloria Payne, ADHS-OCSHCN	We are working with sickle cell for a Medical Home piece. Meeting with folks here in the office and outside. We want to get an overview of how it (medical home) fits with our kids. I will get more information to you next time	*How do sickle cell kids and adults fit into the medical home
	Dr. Attico	What would be helpful is to get a count on the number of adults with sickle cell to try so we can get that program refunded again. Get a count from hospital discharges, hospital admissions, the diagnoses as the state does have this information. Arizona does look at it as a black disease but there are now higher incidences in the Hispanic population here because of the cultural of the state as a whole.	*Count on number of adults with sickle cell – through various measures *Gloria to check system
	Ms. Wendt	Introduced Joan Agostinelli, ADHS-OCSHCN Office Chief	
	Joan Agostinelli, ADHS-OCSHCN	I have a question. You are trying to find out the size of the population that should be seeking services?	
	Mr. Fowler	How many kids in AZ have sickle cell? The disease, not the trait. Of those kids that have it, they have different levels of diagnoses? That would help me.	*How many kids in Arizona have sickle cell? *Of the kids who do have, what's the level of diagnoses?
	Dr. Attico	Then we have the care issue. The kids goes into the ER, they have distrust of ER personnel. The adults have no provider or their care is only at the ER. They fight to get care.	*ER issue with sickle cell patients (younger) seeking help
	Ms. Agostinelli	Would it be helpful if we could identify how many people with sickle cell have hospital visits, emergency department visits by age, or county, by year? We have the hospital discharge records.	*Identify sickle cell hospital visits, emergency dept visits by age, county or year
	Dr. Attico	That's what I am looking for yes. They do report by diagnosis.	*Hospital discharge records research on sickle cell patients. Profile by variables *Gloria and Joan to get together on the specific sickle cell diagnostic codes this would involve
	Ms. Agostinelli	We can't go across databases nicely but we should be able to give you unduplicated count of hospitalized in-patients, unduplicated from those from emergency department visits. We can easily say here's how many people, at each age, in a calendar year of how many people there were at the time of admitting; for one of these diagnosis codes, and they were of age 16, 17, etc. It won't tell you who was	*Project on obtaining count on unduplicated hospitalized in-patients (unduplicated from ER visits)

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		in the hospital last year or this year. It will probably be an undercount of who is living with the problem. But if you have never received this type of information, it will help.	*Will help show the impact of the disease in the state
	Dr. Attico	If we could put this together, we could publish it. It's that important.	
	Ms. Wendt	In summary, the minutes have been reviewed and they are approved. The Community Survey- will be tabled until Dr. Molina returns, and feedback we collected on the Family Profile and they will be forwarded to the Parent Action Council (PAC). Finally, the Arizona Center for Disability Law's training "Educational Rights of Students with Sickle Cell" was highlighted.	
Next Steps/ Assignments	Ms. Wendt	I want to inform you some things. Our community parents have a Leadership Training manual with about 13 sections in it and I would like to segment them out, maybe via email to you and other members for review.  Our e-Learning system is in the process of being tested. That should be up and running soon. We can do more ListSers.	*Parent Leadership Training manual sections to be reviewed by ISG Cultural Competency *E-learning system is being pre-tested for launching soon
Items from the Floor	Group	The group updated each other on current programs and activities.	
	Jana Granillo, Arizona Minority Health	Ms. Granillo from the ADHS Arizona Minority Health Office gave a background on the Arizona Health Disparity Center and the Arizona Minority Health. We have wonderful resources on the website. Access to services, and LEP issues, all that may be useful to the community. It addresses culturally linguistic issues.  Within the website there is information about LEP and information on services under Title VI, the federal mandate that language services must be provided. It helps to advise people of their rights.	Visit <a href="http://www.azminorityhealth.gov">www.azminorityhealth.gov</a> for further information on federal mandates for language services, people's rights, LEP issues, access to services.
	Ms. Payne	Gloria gave a background on the Youth Transition Conference that was held at the AZDOE on September 18 <sup>th</sup> and 19 <sup>th</sup> . The focus was youth transitioning out of programs and/or schools and what they face. The IEP was addressed and they are thinking about a more proactive IEP, meaning for the youth to develop their own with input from all parties (schools, parents, and students). Have the student do the IEP and present to the teacher. There were a lot of representatives from in and out of state.	
	Mr. Fowler	Renaldo talked about some restructuring his office. He said he was excited about Kristine's project as it is a good start. He wants to try and set up something like Saturday conferences so that we can get the parents, the medical people, and the education people get together to put the pieces together.	*Arizona Center for Disability Law possibility of "Saturday informational conferences" for public
	Cozetta LaMore	Expressed concern over the high number of statistics with health disparities in healthcare that are evident, we should think collectively as well as in groups, we need to think of strategies to address this.	* Need strategies to address high number of statistics of health disparities
	Ms. Granillo	Arizona Public Health Association has a Health Disparities section (AZPHA). <a href="http://www.azpha.org">www.azpha.org</a> is the website. They have a health disparity agenda as a top priority. They had a meeting last week whereby they are working on a plan addressing health disparities on a whole. The results from the last meeting are that they will do a survey and try to craft the policy priorities.	*AZPHA/ Arizona Public Health Association has Health Disparities section -currently doing survey to

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			craft their policy priorities Visit <a href="http://www.azpha.org">www.azpha.org</a> for more information.
	Melina Perez-McKenna, CPSA	We just completed our 2006-2007 Cultural Efficiency Plan and Assessment Organization.	
	Ms Wendt.	Thanks for your attendance. Our meetings are scheduled for the rest of the year but we can talk about December's meeting, knowing many people have holiday vacations planned and such.	
Next Meeting		TBD	

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### ISG – PAC Feedback on Community Survey

The ISG Parent Action Council provided feedback (7-13-06) on the ISG Cultural Competency's Community Survey as follows:

- Correlate with AzEIP questionnaire sent to parents (involves a release). AzEIP questionnaire is similar.
- Where will this go?
- What are you trying to accomplish?
- How will it be administered?
- How will results be given back to the community? Results *need* to get back to the community.
- After population has been surveyed, redistribute a thank you back to the surveyed population.
- Do they or will they read and use the information (whoever initiated survey)
- Quantify the results
- Survey will help under-served community needs on reservations